

Evaluating the Balance Between Privacy and Access in Digital Information Sharing

OBJECTIVES: Access to personal health records in an ICU by persons involved in the patient's care (referred to broadly as "family members" below) has the potential to increase engagement and reduce the negative psychological sequelae of such hospitalizations. Currently, little is known about patient preferences for information sharing with a designated family member in the ICU. We sought to understand the information-sharing preferences of former ICU patients and their family members and to identify predictors of information-sharing preferences.

DESIGN: We performed an internet survey that was developed by a broad, multidisciplinary team of stakeholders. Formal pilot testing of the survey was conducted prior to internet survey administration to study subjects.

SETTING: Internet survey.

SUBJECTS: Subjects included English-speaking adults who had an ICU experience or a family member with ICU experience between 2013 and 2016. We used panel sampling to ensure an ethnically representative sample of the U.S. population.

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: One thousand five hundred twenty surveys were submitted, and 1,470 were included in analysis. The majority of respondents (93.6%) stated that they would want to share present and past medical history, either all or that related to their ICU stay, with a designated family member of their choosing. The majority (79%) would also want their designated family member to be able to access that information from a home computer. Although most respondents preferred to share all types of information, they indicated varying levels of willingness to share specific types of more sensitive information. Information-sharing preferences did not differ by age, sex, ethnicity, or type of prior experience in the ICU (i.e., patient or family member).

CONCLUSIONS: In the context of an ICU admission, sharing personal health information with a person of the patient's choosing appears desirable for most patients and family members. Policies and implementation of regulations should take this into consideration.

KEY WORDS: communication; data sharing; digital information; family engagement; intensive care; patient engagement

Although ICUs have achieved impressive success in treating often lethal diseases (1), the burden of ICU treatment is substantial for both patients and their family members (2–4). ICUs have historically been clinician-centered places, arranged for the convenience of physicians and nurses rather than patients and family members. Some pioneers have begun to model a patient-centered (5) alternative to the clinician-centered ICU. Patient-centered care depends on patient and family engagement (PFE), in which patients and family members are full partners with clinicians (6–8), especially through shared decision-making and collaborative care (9–11). Encouraging

Sarah J. Beesley, MD^{1,2,3}

Alex Powell, BS⁴

Danielle Groat, PhD^{1,3}

Jorie Butler, PhD^{5,6,7}

Ramona O. Hopkins, PhD^{1,3,8}

Ronen Rozenblum, PhD, MPH^{9,10}

Hanan Aboumatar, MD, MPH^{11,12}

Allison M. Butler, MStat^{1,2}

Jeremy Sugarman, MD¹³

Leslie Francis, JD, PhD¹⁴

Samuel M. Brown, MD^{1,2,3}

Copyright © 2021 The Author(s). Published by Wolters Kluwer Health, Inc. on behalf of the Society of Critical Care Medicine and Wolters Kluwer Health, Inc. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

DOI: 10.1097/CCM.0000000000005234

PFE and shared decision-making, including the use of formal decision support systems, requires timely, reliable information sharing with family members of critically ill patients (12, 13). In the current ICU milieu, information sharing typically happens face-to-face and piecemeal without clear guidance on how and when to divulge what pieces of information. Family members commonly report that they desire much more information about their loved one (14, 15).

Health information technology and patient/family facing e-health tools have become central to promoting patient engagement and empowerment through better communication with providers (16, 17). In order to become more patient centered, improve communication, and facilitate PFE, electronic personal health records (PHRs; often called electronic portals or electronic medical records [EMRs]) have been developed in a variety of healthcare environments (18, 19). Despite mixed results, data are increasingly emerging to support the role of PHRs in improving patient-centered care delivery, health services efficiency, and health outcomes (17, 18, 20, 21).

In this study, we sought to measure ICU patient and family attitudes surrounding sharing of EMR information with family members. This included eliciting general preferences both for and against sharing as well as willingness to share specific categories of information (e.g., medication lists, past medical history). Secondarily, we sought understanding surrounding predictors that identified individuals who would have concerns about sharing of EMR information.

METHODS

Survey Development

The survey was iteratively developed by a team of privacy legal scholars, ethicists, methodologists, health services researchers, clinicians, and specialists in critical care, patient-centered care, and engagement. Intermountain Healthcare's Patient and Family Advisory Council also collaborated in designing and reviewing the survey instruments. Formal pilot testing of the survey was conducted with two groups of respondents at Intermountain Medical Center (20 respondents total), including family members of patients who had recently been discharged from an ICU and individuals present in waiting rooms of outpatient clinics, including pulmonary, cardiology, internal medicine,

and trauma follow-up clinics. Pilot testing was used to refine the survey. The final version of the survey (administered to all the respondents) is included in the online data supplement (**Supplemental Privacy Questionnaire**, <http://links.lww.com/CCM/G805>).

Participants

We employed the Qualtrics Internet empanelment procedure, a technique commonly used in medical surveys (22–24), to administer the survey to our target population. This empanelment procedure allows researchers to preselect desired demographic coverage, and then, a sample of individuals meeting the demographic criteria are asked to complete the survey. Criteria included age greater than 18 years, English speaking, and if they or their family member had an ICU experience between 2013 and 2016. To assure an ethnically representative sample of the U.S. population, we directed panel sampling to meet the following proportions: non-Latino White 66%, African or African American 13%, Asian 5%, Hispanic/Latino 14%, and other 2%. Survey responses were collected from January 13, 2017, to January 24, 2017.

Survey Description

The survey examined the following broad areas: respondent descriptors and demographics, respondent self-perception of their quality of life, and information-sharing preferences. Specifically, respondents were asked to provide their demographic information, experience with online sources of health information, experience working in healthcare, and whether their ICU experience was as a patient or family member. They were also asked to indicate how they perceived their own quality of life.

The remainder of the survey focused on examining respondents' preferences regarding sharing their personal information in an ICU setting. To do this, respondents were first asked to imagine their own hypothetical future treatment in an ICU where they had designated a person to be able to speak on their behalf. As they answered questions regarding information-sharing preferences, they were asked to think about the specific person they would want as their designated individual. In this context, we asked respondents the amount of information they would want to share with their designated person, whether they would want their designated

person to be able to access their health information from a home computer, and preferences on specific categories of information to be potentially shared with their designated person. Answer choices were presented in either Likert-style format or in another ordinal format.

Information-sharing preferences were first elicited by presenting respondents with the hypothetical question: “If I were unable to communicate my opinions in the hospital, I would want my designated person to have access to...” and asking them to choose from the following responses: “1. My entire medical record, including all of my past history”; “2. All of my medical information relevant to making decisions on my behalf in the ICU, including relevant past history”; “3. Only medical information from the current hospitalization”; and “4. I would not want to share any of my medical information.”

To assess the potential relationship between quality of life and willingness to share personal health information (PHI), we employed the EuroQol EQ-5D-3L instrument (25). The EQ-5D-3L is a widely used measure of general quality of life and assesses five dimensions of health status: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. It is a validated health utility score, with higher scores indicating better quality of life. We also used the standard EQ-5D-3L Visual Analog Scale.

To assess detailed preferences regarding specific categories of information, respondents were given a list of 15 types of potentially more sensitive information and asked to indicate their preference for sharing each on a five-point Likert scale. Examples of these categories include sexual history and mental health records.

Short-form text entry responses were used to elicit specific concerns regarding sharing information in the proposed hypothetical ICU admission—“What would worry me the most about having [my designated person] having access to my medical information is...”

We included an attention question in order to exclude respondents who failed to read question prompts (i.e., respondents were instructed to “respond ‘strongly agree’ to a question” and only if they responded correctly were they included in the analysis).

Data Analysis

Descriptive statistics of demographic characteristics, survey responses, and information-sharing preferences were described by counts and percent of population or as the median and interquartile range (IQR). Responses to the short answer question were

qualitatively analyzed by four authors (S.J.B., A.P. J.B., R.O.H.), which included an experienced qualitative analyst (J.B.) to determine common themes.

We dichotomized responses based on willingness versus unwillingness to share any level of information. We then used logistic regression (with Firth regression where outcomes were rare) to evaluate the relevance of candidate predictors to willingness to share information, including demographic descriptors, previous exposure to EMRs, and quality of life assessments.

Predictors of Information-Sharing Preferences

We explored the relationship between demographic characteristics and preferences for information sharing both on a basic level of willingness to share as well as preferences regarding remote access to that information. We hypothesized a priori that age, sex, ethnicity, prior experience with electronic health records, and type of previous ICU experience could be associated with preferences for information sharing.

All statistical analyses were performed in R Software (4.0.0; R Foundation for Statistical Computing, Vienna, Austria; <https://www.R-project.org/>).

Ethical Considerations

The Intermountain Institutional Review Board (IRB) approved the study with a waiver of documentation of consent (IRB number 1050043). An introduction to the electronic survey stated that completion of the survey constituted consent. Respondents received minor compensation according to standard Qualtrics procedures.

RESULTS

Surveys were collected from 1,520 respondents through the empanelment procedure; 1,470 of these were complete and included in the analysis. Median (IQR) of age was 36 years (27–54 yr) with participants ranging in age from 18 to 87 years old. Two-thirds (66%) identified as female. Among respondents, 664 (43.7%) were prior ICU patients, whereas 808 (53.2%) were a family member of a prior ICU patient. Forty-eight respondents (3.2%) had been both a patient and a family member in the ICU. Patients were ethnically and racially representative as specified. One hundred fifty-two respondents (10%) worked in healthcare,

and 40% had a close friend or family who worked in healthcare (**Table 1**).

Seven hundred eighty-one respondents (51.4%) had accessed their own medical record electronically in the past, and most of these, 609 (78%), accessed the record via an online portal. Additionally, 323 (41.4%) accessed their own EMR information via a website, 173 (22.2%) by e-mail, and 42 (5.4%) via text messaging. When using a website, the majority used their hospital website 228 (70.6%) or the physician’s website 145 (45%).

Respondents who had accessed their EMR did so for the following reasons: get tests results (79%), get information about health conditions (54%), review notes by healthcare provider (47%), make appointments (44%), communicate with healthcare provider (39%), refill

medications (33%), or review medication doses (17%). Almost half of respondents (47%) had communicated with their healthcare provider electronically. Most of these communicated using e-mail (55%), the online EMR (48%), or texting (33%). Ten percent used a website for communication.

If respondents were unable to communicate their preferences, almost all respondents (99%) would want their designated person to have access to at least some of their medical records. Over half (56%) would want their designated person to have access to the entire record, including all past history, whereas 37% would want this information restricted to that relevant to making decisions on their behalf in the ICU and 6% would only want information from the current hospitalization shared.

If the designated person was at home and not in the hospital, most respondents (79%) would want the designated person to have access to their medical information from a home computer. Also, most respondents (71%) also thought that having this access would emotionally help their designated person during their illness, whereas only 8% thought it would not be emotionally helpful for a family member to have this information.

Respondent preferences for sharing specific types of information followed the same general pattern as broad sharing preferences with more than half of respondents choosing either “agree” or “strongly agree” to all but one of the listed categories. See **Table 2** for detailed results on respondent preferences. The outlying informational category was “Whether I have a criminal record” where only 49.7% of respondents indicated a willingness to share. Although this information is not a routine piece of every patient’s medical record, it is possible that previous incarceration or treatment at a correctional institution could be clinically relevant (e.g., tuberculosis exposure) and included in a patient’s history.

TABLE 1.
Respondent Demographics (N = 1,470)

Attribute	Central Tendency (Dispersion)
Age, yr, median (IQR)	36 (27–54)
Self-reported gender, n (%)	
Female	971 (66.1)
Male	493 (33.5)
Other	6 (0.4)
Race, n (%)	
Non-Latino White	974 (66.3)
Black or African American	190 (12.9)
Hispanic-Latino	156 (10.6)
Asian	70 (4.8)
American Indian, Alaskan Native, Native Hawaiian, or Pacific Islander	7 (0.5)
More than one race	65 (4.4)
Do not wish to report	8 (0.5)
Works in healthcare, n (%)	146 (9.9)
Family or friend in healthcare, n (%)	584 (39.7)
ICU experience within last 3 yr, n (%)	
Family member	777 (52.9)
Self	646 (43.9)
Self and family member	47 (3.2)
EQ-5D ^a utility index, median (IQR)	1.4 (1.2–1.6)
EQ-5D ^a Visual Analog Scale, median (IQR)	80 (66–90)

IQR = interquartile range.

^aEuroQol EQ-5D-3L instrument is a validated health utility score, with higher scores indicating better perceived health.

Predictors of Information-Sharing Preferences

A Firth regression analyzing demographic category and willingness to share any information revealed no significant relationship between the two variables (**eTable 1**, <http://links.lww.com/CCM/G806>). We found that male sex (odds ratio [OR], 1.73; CI, 1.18–2.56), previous experience online medical records and/or clinician communication (OR, 2.30; CI, 1.48–3.55), and previous admission to the ICU (OR, 1.47; CI, 1.03–2.10) were

TABLE 2.
Willingness to Share Information With a Designated Other (N = 1,520), Reported as n (%)

Information	Strongly Disagree	Disagree	Neither Disagree Nor Agree	Agree	Strongly Agree
Laboratories, x-rays, and surgery results while in the ICU	38 (2.5)	18 (1.2)	48 (3.2)	520 (34.2)	896 (58.9)
Prior pregnancy history, including loss or termination (females only, N = 999)	83 (8.3)	138 (13.8)	121 (12.1)	258 (25.8)	399 (39.9)
Marital or relationship status	48 (3.2)	63 (4.1)	190 (12.5)	479 (31.5)	740 (48.7)
Events leading to the ICU admission	19 (1.2)	23 (1.5)	73 (4.8)	504 (33.2)	901 (59.3)
Mental health records (e.g., depression, anxiety, schizophrenia, prior suicide attempts)	62 (4.1)	95 (6.2)	177 (11.6)	463 (30.5)	723 (47.6)
History of substance use or addictions	81 (5.3)	105 (6.9)	194 (12.8)	468 (30.8)	672 (44.2)
Sexual orientation	131 (8.6)	126 (8.3)	265 (17.4)	398 (26.2)	600 (39.5)
Whether respondent currently has cancer	45 (3)	38 (2.5)	76 (5)	492 (32.4)	869 (57.2)
Whether respondent currently has a terminal condition	47 (3.1)	38 (2.5)	81 (5.3)	454 (29.9)	900 (59.2)
Whether respondent has a sexually transmitted disease	128 (8.4)	148 (9.7)	196 (12.9)	429 (28.2)	619 (40.7)
Whether respondent has a criminal record	255 (16.8)	235 (15.5)	274 (18)	275 (18.1)	481 (31.6)
Religious affiliation/church membership	190 (12.5)	146 (9.6)	282 (18.6)	322 (21.2)	580 (38.2)
Medications respondent is taking now or has taken in the past	35 (2.3)	44 (2.9)	93 (6.1)	467 (30.7)	881 (58)
Allergies	18 (1.2)	15 (1)	48 (3.2)	397 (26.1)	1,042 (68.6)
Daily status while in the ICU	15 (1)	10 (0.7)	47 (3.1)	416 (27.4)	1,032 (67.9)

associated with greater likelihood of willingness to allow access to information from a home computer by their designated person. Lower health-related quality of life (as judged by the EQ-5D Visual Analog Scale) was slightly but significantly associated with less willingness to share in this setting (OR, 0.99; CI, 0.98–1.00).

Free-Text Responses

Eigh hundred eighty unique text responses about respondents' greatest concerns regarding sharing their EMR with their designated other were recorded and analyzed. Six major themes were identified: no concerns, sensitive history, possible burden on the designated other, information security, concerns about abuse of the information by the designated other, and lack of confidence in their designated other. These themes illustrate the wide spectrum of reasons that respondents may be concerned about sharing their information. Some respondents expressed concern that

they themselves could be harmed by sharing information (2.6% of respondents), whereas other respondents indicated a concern that sharing their information would create a burden for their designated other (5% of respondents.) Full descriptions of these themes and representative quotations are given in **Table 3**.

DISCUSSION

Our results provide insight into patient willingness to include trusted individuals in matters that would otherwise be private in order to provide access to family members in an ICU setting. Broadly, almost all respondents were willing to allow a designated family member to see at least some of their information (99%). Even at the most expansive version of sharing, granting access to all medical records and history regardless of relevance to current hospitalization, over half of respondents (56%) were willing to grant that access to their designated family member.

TABLE 3.
Primary Results of Qualitative Analysis

Theme	Example Response
No concerns—Respondent states that they have no reservations about their designated person having access.	“Nothing would bother me because I would choose someone close to me that I can trust.”
Sensitive history—Does not want to share things like pregnancy history, drug use, sexuality, religion.	“If I had a previous condition that I was embarrassed about I wouldn’t want them to know that if it wasn’t relevant to my current care.”
Burden—Respondent is worried that the information would create an emotional burden on designated person.	“They would worry and stress more about my condition which would cause their deterioration.”
Data security—Respondent is worried the information will be accessed by people other than their designated person.	“Someone else getting the information, and possibly leading to identity theft.”
Abuse—Respondent is concerned that sharing their information with their designated other will create potential for abuse of some kind.	“Holding things they don’t like over me later.”
Poor proxy—Respondent is concerned that information would lead designated person to make decisions that the respondent would not make themselves.	“Not making the right decisions based on the facts they have in front of them.”

Respondents’ willingness to share granular types of information with a designated family member was in each category lower than the average willingness to broadly share all information. This is an unsurprising outcome given that certain classes of information (e.g., mental health and reproductive history, sexual history, or certain stigmatized diseases like HIV) are often extremely private matters for patients (26, 27). However, only a minority of systems allow for such management (28).

Context is an important factor in determining patient preference for sharing PHI with others. Although only a minority of patients seem to wish to grant *carte blanche* to access to others in a general setting (29), when family members are directly involved in treatment that preference is reversed and the majority of patients prefer to share their information (30, 31).

Concerns regarding security of information were reflected in free-text responses in our survey. There are a variety of healthcare environments that include OpenNotes (an organization which advocates for patient access to the clinical notes recorded by treating clinicians) (32)—by which patients have access to clinical documentation. Although some of these environments include the ability to establish proxy access for adult caregivers, the process for doing so can be quite burdensome (33). In the absence of formalized proxy access, patients may share their own access credentials with a caregiver (33). A possible proxy access policy would give patients the ability to proactively restrict certain kinds of information from future access by a

designated person, such as sensitive information relating to sexual or mental health.

Given that data security breaches are distressingly common, attempts to increase access to PHI may be viewed with suspicion (34). Generally, respondents seemed concerned that granting access to their designated family member would precipitate a situation wherein a third party with malicious intent might gain access as well. Nationally, the current trend is to increase patient access to EMR data, and with the upcoming implementation of the 21st Century Cures Act Final Rule, patients will be legally owed immediate access to their information, including imaging narratives, procedure notes, and pathology reports (35). Access to these data by designated family will be important to navigate as well.

Another important consideration in interpreting our results is that we did not evaluate the familiarity of respondents with the information contained in the EMR. It is likely that patients generally do not have a comprehensive understanding of all the information that is included in an EMR (36). Although misunderstanding the content of the EMR could affect the responses to our survey, it is important to note that in all but one specific category of information (criminal history), the majority of respondents would choose to provide that information with their designated family member.

Despite the strengths of our findings, we acknowledge that the hypothetical nature of an anticipated ICU admission may have introduced bias, although preference

elicitation about personal EMRs may commonly happen in premorbid settings, and we restricted our cohort to individuals who had actual experience with ICU admission. We thus anticipate that such bias, if present, is consistent with how such preferences could be obtained in actual settings and therefore would seem valid.

This study is also limited by only including respondents fluent in English. An important next step would be to administer a similar survey in alternative languages to further understand any potential differences in sharing preferences.

We also acknowledge that an internet survey excludes individuals who do not use computer technology or who do not have ready access to computers. Our observation that respondents with greater experience using information technology in medical environments are more willing to share information suggests that our results may not generalize to the occasional patients who do not use computer technology. Reaching patients who do not have access to computers due to socioeconomic barriers is more challenging and limits our generalizability to this portion of the population. A potential solution would be to increase access to computer facilities in the community and in healthcare settings.

CONCLUSIONS

Most respondents to an internet survey would want their family to have access to all relevant health information if they were unable to decide for themselves. Regulatory guidance and local policies should take such observations into consideration.

- 1 Division of Pulmonary and Critical Care Medicine, Department of Internal Medicine, Intermountain Medical Center, Murray, UT.
- 2 Division of Pulmonary and Critical Care Medicine, Department of Internal Medicine, University of Utah School of Medicine, Salt Lake City, UT.
- 3 Center for Humanizing Critical Care, Intermountain Healthcare, Murray, UT.
- 4 University of Utah School of Medicine, University of Utah, Salt Lake City, UT.
- 5 Division of Geriatrics, University of Utah School of Medicine, Salt Lake City, UT.
- 6 Geriatrics, Research, Education and Clinical Center (GRECC), VA Salt Lake City Healthcare System, Salt Lake City, UT.
- 7 Informatics, Decision Enhancement, and Analytic Sciences (IDEAS), VA Salt Lake City Healthcare System, Salt Lake City, UT.

- 8 Department of Psychology and Neuroscience Center, Brigham Young University, Provo, UT.
- 9 Division of General Internal Medicine and Primary Care, Brigham and Women's Hospital, Boston, MA.
- 10 Harvard Medical School, Boston, MA.
- 11 Armstrong Institute for Patient Safety and Quality, Johns Hopkins School of Medicine, Baltimore, MD.
- 12 Division of General Internal Medicine, Department of Medicine, Johns Hopkins School of Medicine, Baltimore, MD.
- 13 Berman Institute of Bioethics, Department of Medicine, and Department of Health Policy and Management, Johns Hopkins University, Baltimore, MD.
- 14 Quinney College of Law and Department of Philosophy, University of Utah, Salt Lake City, UT.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website (<http://journals.lww.com/ccmjjournal>).

Supported, in part, by The Gordon and Betty Moore Foundation.

Drs. Beesley and Rozenblum received support for article research from The Gordon and Betty Moore Foundation. Dr. Powell received funding from the University of Utah School of Medicine. Dr. Butler disclosed government work. Dr. Hopkins' institution received funding from Intermountain Research and Medical Foundation. Drs. Rozenblum's, Aboumatar's, and Brown's institutions received funding from The Gordon and Betty Moore Foundation. Dr. Rozenblum disclosed having equity in Hospitech Respiration Ltd. Dr. Sugarman is a member of Merck KGaA's Bioethics Advisory Panel and Stem Cell Research Oversight Committee; a member of IQVIA's Ethics Advisory Panel; a member of Aspen Neurosciences Scientific Advisory Board; a member of a Merck Data Monitoring Committee; a consultant to Biogen; and a consultant to Portola Pharmaceuticals Inc. None of these activities are related to the material discussed in this article. Dr. Sugarman received funding from Merck KGaA Bioethics Advisory Panel and Stem Cell Research Oversight Committee, IQVIA Ethics Advisory Panel, and Merck Data Monitoring Committee. The remaining authors have disclosed that they do not have any potential conflicts of interest.

For information regarding this article, E-mail: sarah.beesley@gmail.org

REFERENCES

1. Zimmerman JE, Kramer AA, Knaus WA: Changes in hospital mortality for United States intensive care unit admissions from 1988 to 2012. *Crit Care* 2013; 17:R81
2. Halpern NA, Pastores SM: Critical care medicine in the United States 2000-2005: An analysis of bed numbers, occupancy rates, payer mix, and costs. *Crit Care Med* 2010; 38:65-71
3. Cooper LM, Linde-Zwirble WT: Medicare intensive care unit use: Analysis of incidence, cost, and payment. *Crit Care Med* 2004; 32:2247-2253
4. Mullins PM, Goyal M, Pines JM: National growth in intensive care unit admissions from emergency departments in the

- United States from 2002 to 2009. *Acad Emerg Med* 2013; 20:479–486
5. National Research Council: Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC, The National Academies Press, 2001
 6. Carman KL, Dardess P, Maurer M, et al: Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)* 2013; 32:223–231
 7. Department of Health: Helping the NHS Put Patients at the Heart of Care: The Patient and the Public Engagement Support Programme 2009–10. London, United Kingdom, Department of Health, Patient and Public Engagement, 2009
 8. Berger Z, Flickinger TE, Pfoh E, et al: Promoting engagement by patients and families to reduce adverse events in acute care settings: A systematic review. *BMJ Qual Saf* 2014; 23:548–555
 9. Chewning B, Bylund CL, Shah B, et al: Patient preferences for shared decisions: A systematic review. *Patient Educ Couns* 2012; 86:9–18
 10. Davidson JE, Powers K, Hedayat KM, et al; American College of Critical Care Medicine Task Force 2004–2005, Society of Critical Care Medicine: Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med* 2007; 35:605–622
 11. Brown SM, Rozenblum R, Aboumatar H, et al: Defining patient and family engagement in the intensive care unit. *Am J Respir Crit Care Med* 2015; 191:358–360
 12. Cox CE, Lewis CL, Hanson LC, et al: Development and pilot testing of a decision aid for surrogates of patients with prolonged mechanical ventilation. *Crit Care Med* 2012; 40:2327–2334
 13. Cox CE, White DB, Abernethy AP: A universal decision support system. Addressing the decision-making needs of patients, families, and clinicians in the setting of critical illness. *Am J Respir Crit Care Med* 2014; 190:366–373
 14. Azoulay E, Pochard F, Chevret S, et al; French FAMIREA Group: Meeting the needs of intensive care unit patient families: A multicenter study. *Am J Respir Crit Care Med* 2001; 163:135–139
 15. Davidson JE, Daly BJ, Agan D, et al: Facilitated sensemaking: A feasibility study for the provision of a family support program in the intensive care unit. *Crit Care Nurs Q* 2010; 33:177–189
 16. Rozenblum R, Miller P, Pearson D, et al: Information Technology for Patient Empowerment in Healthcare. Berlin, Germany, Walter de Gruyter Inc, 2015
 17. Rozenblum R, Miller P, Pearson D, et al: Patient-centered healthcare, patient engagement and health information technology: The perfect storm. In: Information Technology for Patient Empowerment in Healthcare. Grando MA, Rozenblum R, Bates DW (Eds). Berlin, Germany, Walter de Gruyter Inc, 2015
 18. Wells S, Rozenblum R, Park A, et al: Personal health records for patients with chronic disease: A major opportunity. *Appl Clin Inform* 2014; 5:416–429
 19. Wells S, Rozenblum R, Park A, et al: Organizational strategies for promoting patient and provider uptake of personal health records. *J Am Med Inform Assoc* 2015; 22:213–222
 20. Archer N, Fevrier-Thomas U, Lokker C, et al: Personal health records: A scoping review. *J Am Med Inform Assoc* 2011; 18:515–522
 21. Ammenwerth E, Schnell-Inderst P, Hoerbst A: The impact of electronic patient portals on patient care: A systematic review of controlled trials. *J Med Internet Res* 2012; 14:e162
 22. Barr PJ, Thompson R, Walsh T, et al: The psychometric properties of CollaboRATE: A fast and frugal patient-reported measure of the shared decision-making process. *J Med Internet Res* 2014; 16:e2
 23. Rosoff H, John RS, Prager F: Flu, risks, and videotape: Escalating fear and avoidance. *Risk Anal* 2012; 32:729–743
 24. Brown SM, Bell SK, Roche SD, et al: Preferences of current and potential patients and family members regarding implementation of electronic communication portals in intensive care units. *Ann Am Thorac Soc* 2016; 13:391–400
 25. Group TE: EuroQol—a new facility for the measurement of health-related quality of life. *Health Policy* 1990; 16:199–208
 26. Francis LP: Skeletons in the family medical closet: Access of personal representatives to interoperable medical records. *Louis UJ Health L & Pol'y* 2010; 4:371
 27. Soni H, Grando A, Murcko A, et al: State of the art and a mixed-method personalized approach to assess patient perceptions on medical record sharing and sensitivity. *J Biomed Inform* 2020; 101:103338
 28. Wolff JL, Kim VS, Mintz S, et al: An environmental scan of shared access to patient portals. *J Am Med Inform Assoc* 2018; 25:408–412
 29. Teixeira PA, Gordon P, Camhi E, et al: HIV patients' willingness to share personal health information electronically. *Patient Educ Couns* 2011; 84:e9–e12
 30. Semere W, Crossley S, Karter AJ, et al: Secure messaging with physicians by proxies for patients with diabetes: Findings from the ECLIPPSE study. *J Gen Intern Med* 2019; 34:2490–2496
 31. Wolff JL, Aufill J, Echavarría D, et al: Sharing in care: Engaging care partners in the care and communication of breast cancer patients. *Breast Cancer Res Treat* 2019; 177:127–136
 32. Delbanco T, Walker J, Bell SK, et al: Inviting patients to read their doctors' notes: A quasi-experimental study and a look ahead. *Ann Intern Med* 2012; 157:461–470
 33. Latulipe C, Mazumder SF, Wilson RKW, et al: Security and privacy risks associated with adult patient portal accounts in US hospitals. *JAMA Intern Med* 2020; 180:845–849
 34. Büschel I, Mehdi R, Cammilleri A, et al: Protecting human health and security in digital Europe: How to deal with the “privacy paradox”? *Sci Eng Ethics* 2014; 20:639–658
 35. Office of the National Coordinator for Health Information Technology (ONC) Department of Health and Human Services (Ed): 21st century Cures Act. Washington, DC, Department of Health and Human Services. 2020, pp 320. Available at: <https://www.healthit.gov/cures/sites/default/files/cures/2020-03/TheONCCuresActFinalRule.pdf>. Accessed September 1, 2021
 36. Caine K, Tierney WM: Point and counterpoint: Patient control of access to data in their electronic health records. *J Gen Intern Med* 2015; 30(Suppl 1):S38–S41